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# USING PATIENTS' VIEWS TO ENHANCE INFORMATION AND SUPPORT PROVIDED FOLLOWING DIAGNOSIS OF CANCER

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## Abstract

*Background* Information plays a key role in the adaptation of cancer patients to the demands placed upon them by their disease and its treatment. Health professionals need to fully understand the needs of people who have cancer in order that services provided are properly designed and delivered.

*Aim* The aim of this study was to examine patients' views of the information and support available to them, and to determine what improvements they would suggest.

*Method* Patients (302 respondents from 500 sent) with all types of cancer, excluding non-melanomatous skin cancer, were sent a questionnaire enquiring about key issues in information and support following the diagnosis of cancer.

*Results* Overall the response rate was 60.4%. Most patients (73%) felt they received adequate information. However one third stated that there was insufficient support available on completion of treatment. Medical practitioners were identified as the most popular source of initial information, however a significant number (11% of consultants and 25% of GPs) were rated unfavourably. Written information was rated poorly by 42% of respondents. Although specialist nurses and support staff were rated as key players in the care and treatment process, difficulties for patients in accessing them were identified.

*Conclusion* Despite a general satisfaction with information and support provision, significant gaps in service provision such as poor communication and problematic, inter-disciplinary referral procedures were reported. Key issues for the future development of information and support services provided for people who have cancer such as the development of a cancer specific information centre were identified.

**Key words:** Information needs, cancer, sources of information, information centre

## Introduction

A diagnosis of cancer, of whatever type, can trigger a crisis reaction for the person involved and their family. Such a reaction can often be characterised by its intensity (Krause, 1991). When faced with a situation that is threatening, a person will often seek information to better understand what is happening (Lazarus & Folkman, 1984) and to begin the process of identifying potential areas of support. Support, in terms of the provision of information, is an essential aspect of all health care professionals' roles (Ream & Richardson, 1996). Providing patients with information about their diagnosis and treatment is recognised as having a positive value in assisting them to cope with their illness (Cassileth et al, 1980; Blanchard et al, 1988; Meredith et al, 1996; Graydon et al, 1997). Lack of information, misdirected or inadequate information can cause distress, anxiety

and dissatisfaction (Meredith et al, 1996). Better understanding of patients' perspectives on information required and its mode of transmission is needed, as it might be argued that when information provision is effective, patients may be more intensely involved in their care. This paper aims to investigate patients' views on the information and support services available following a diagnosis of cancer and to offer suggestions on how services might be improved in these areas.

## Background

Informational needs following a diagnosis of cancer. Patients receiving a diagnosis of cancer, where they perceive that diagnosis itself to be a threat, may begin to utilise coping strategies. Seminal evidence exists to support the fact that information may help patients

sustain hopeful attitudes (Cassileth et al, 1980) and assists them to cope with their illness. (Blanchard et al, 1988; Meredith et al, 1996; Graydon et al, 1997).

Degner et al (1989) identified nine specific information needs, derived from an extensive review of the literature. Studies examined in relation to these information needs found that the top three priorities addressed survival issues (Chalmers et al, 2001; Derdarian, 1987; Bilodeau & Degner, 1996; Luker et al, 1995; Luker et al, 1996; Davison et al, 1995; Harrison-Woermke & Graydon, 1993; Galloway et al, 1997; Graydon et al, 1997; Wiggers et al, 1990). Other key findings from these studies can be seen in table 1. Although individually these studies have limitations relating to sample size and methodology used, collectively their findings support Degner et al's (1989) work on informational needs for patients.

### Preferred sources of information

Consultant doctors are repeatedly identified as the preferred source of information, with percentages ranging from 60% to 97% (Meredith et al, 1996; Bilodeau and Degner, 1996; Hinds et al, 1995; Slevin et al, 1996; Luker et al, 1996; Veronesi et al, 1999).

When examining the role of the nurse as a source of information, the picture is more complicated. Bilodeau and Degner (1996) found nurses were ranked second as the patients' (n=74) most preferred source and were third as the actual source of information. Nurses' ranking as a source of information being higher than their actual rating regarding service delivery suggests nurses may be failing to meet patients' information needs. Other studies support this finding, claiming that when compared with patients' expressed information needs, nurses' understanding of these needs are often ill-informed (Harrison-Woermke & Graydon, 1993; Suominen et al, 1995).

Clinical Nurse Specialists (CNS) are perceived as an important source of information. Evans (1995) found all respondents (n=33) who had contact with CNS's expressed respect and gratitude for the

enormous support they gained from them. Limitations include a small sample size, predominantly female (n=26) and low response rate (33%). Luker et al (1996) and Chalmers et al (2001) found breast care nurses were ranked as the second most important source of information for patients secondary to consultants and GPs respectively.

Slevin et al (1996) distributed questionnaires (n=431) covering the use of different sources of information. Fifty percent of patients reported ward sisters as a significant source of information, being the third highest ranked source.

Support and information from families and friends have been cited in many studies as an important source (Codd, 1999; Annett, 2000; Northouse, 1989; Shingler, 1997). Annett (2000) interviewed 10 patients and found that family members provided most of the support. A limitation of this study is the very small sample size. Shingler (1997) found 100% of their respondents (n=300) attending oncology clinics, sought additional information using sources of TV (13%), newspapers (25%), support groups (36%), friends (20%) and the Internet (15%). In spite of the large sample, it is difficult to generalise these findings as not all patients attend oncology clinics.

Some studies support the finding that voluntary organisations and support groups play an important role in providing information (Evans, 1995; Shingler, 1997; Adams, 1991). Others report that patients perceive that they received little useful information from these services (Luker et al, 1996; Slevin et al, 1996; Boudioni et al, 1999; Veronesi, 1999; Codd, 1999; Chalmers et al, 2001). Boudioni et al (1999) found that patients availing of telephone helplines were predominantly female (78%), middle class and between the ages of 50 – 59 years.

### Methods of information provision

When considering information for patients, it is important to understand the medium through which information is conveyed, as the way in which people are informed of their disease can have a lasting psychological or emotional effect. Various sources have suggested that verbal information is by far of most importance to patients (Bilodeau and Degner, 1996; Knowles et al, 1999; Cheater, 1999; Cortis and Lacey, 1996). Rees and Bath (2000) from an extensive literature review purported that women prefer verbal information from health care professionals at time of diagnosis. Further from diagnosis women prefer mass media sources of information.

Written information can be extremely beneficial for patients in assisting them to clarify details and reinforce information when supplementing verbal information (Knowles, 1999; Griffiths and Leek,

**Table 2: Most common types of cancer were represented in the study, with breast cancer dominant**

Cancer Type	no	%
Breast*	91	30.1
Bowel/stomach/oesophagus/throat**	59	19.5
Bladder/prostate/kidney	57	18.9
Leukaemia/lymphoma	32	10.6
Skin/lung/testes/humerus/penis	34	11.2
Ovarian/uterus/cervix	29	9.6

\*includes 1 patient with a combination of breast and bowel

\*\*includes 1 patient with a combination of bowel and liver



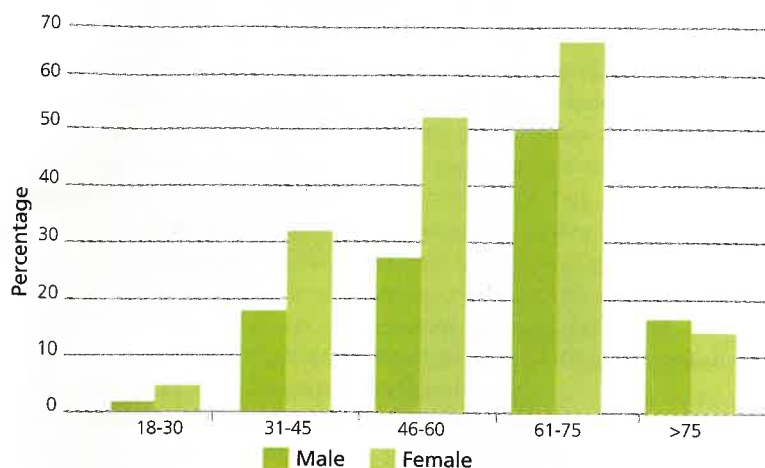


Figure 1: The distribution of age against gender in the 302 patients studied, of which 181 (60%) were female and 121 (40%) male

1995; Harris, 1997; Hinds, 1995). However patients do not always receive written information. Scriven and Tucker (1997) reported only 35% of the hospitals investigated in their study provided leaflets. Cheater et al (1999) and Logge et al (1997) reported similar findings with less than half of the patients studied ( $n = 449$ ), and 20% of patients ( $n=497$ ) respectively, having received written information. While written information can play an important role in supplementing and re-enforcing verbal information, the information, they contain must be accurate, comprehensive and relevant (Coulter, 1998). Myers and Kunkel (2000) found that written information supplemented with audio-visual aids and computer programs are beneficial in preparing patients to play a more active role in their care. Alternatively they may forget receiving information leaflets, or the documentation may not be appropriate, they may be unable to read or have vision disability.

What has become clear, is that patients have differing information needs. The way individuals feel physically and psychologically will determine how much information they can absorb. Illness may lead to feelings of vulnerability. All health care professionals should assess their individual patients' needs and then provide information appropriate to their stage of disease (Mills & Sullivan, 1999; Drew & Fawcett, 2002). Accurate information which patients find useful has an empowering effect and the potential to enhance the quality and appropriateness of health care.

This work was completed within the population of cancer patients of the Southern Health and Social Services Board, part of the UK National Health Service (NHS). The NHS was set up just over 50 years ago and is now the largest organisation in

Europe. It is recognised as one of the best health services in the world by the World Health Organisation

### The Study

#### Purpose and aims

The aims of this study were to understand how information and support needs of patients with cancer were currently being met and secondly respondents views on the development of an cancer information centre.

#### Methods

A retrospective approach was chosen to ensure that patients had prior experience of diagnosis, treatment and aftercare. A quantitative approach allowed the collection of data from large numbers of patients and facilitated the use of statistical analysis to draw conclusions.

#### Ethical issues and approval

Approval was sought from the medical directors of the hospitals involved and General Practitioners (GPs) of those respondents who took part in the study. Within a covering letter accompanying the questionnaire, patients were invited to take part. Return of the questionnaire implied consent to participate.

#### Sample selection

The sample size required for the study was based on the regional cancer registry statistics wherein 1400 patients are registered yearly with a cancer within the catchment area. Analysis of cancer groups from the registry demonstrated one third of these patients had non-melanomatous skin cancer, which is simply treated, justifying their exclusion to prevent skewing of results. Using a confidence level of 95% and an expected response rate of 45% (Travis, 1999), the required sample size was calculated at 588.

The sample was generated from Patient Administration Systems in the three hospitals involved. Recruitment of patients was carried out utilising the International Classification of Diseases. Exclusions were children less than 18 years, persons with learning disabilities and patients in the terminal stages of cancer or ill health.

Patients' names were generated into GP practice lists and the practices contacted, to ascertain the patients' current state of health. As a result of this the total population which could be included totalled 500. Therefore sampling was unnecessary; the entire eligible population was included.

#### Research instrument

The questionnaire was adapted from Travis (1999). Presentation to several experts, as well as checking by

a multi-disciplinary group ensured face validity. It consisted of two sections. Section one enquired of respondents views of the information and support they had received when they had been diagnosed with cancer. It utilised closed questions, Likert and rating scales. Section two enquired of patients views of the development of an information centre and utilised closed questions, rating scales and an open question. A pilot study of 12 patients further validated the questionnaire. Comments were acknowledged and the questionnaire adjusted accordingly. The questionnaire was coded for analysis using the software package Epi-Info.

The questionnaires were posted to the eligible population. A nil return form provided patients with the opportunity to actively decline from taking part in the study. Respondents were allowed two weeks to complete and return the questionnaire. Reminders were sent out to the non-responders three weeks after the initial return date, yielding a further response of 12%.

## Results

### Response rate

The overall response rate for patients participating in the study was 76.4% (n=382), of which 16.0% (n=80) responded wishing not to take part in the study by the completion of the nil return form and 60.4% (n=302) patients responded by completion of the questionnaire. The ratio of male to female respondents was 40:60, and the age distribution ranged from 18 years to 85 years. The most common (mode) age group for both male and female respondents was 61-75 years (see figure 1).

### Diagnosis and treatments

Patients' diagnosis are categorised into related groups and can be seen in table 2. Respondents with breast cancer represented the largest group of patients (30.1%), compared with the lung cancer patients (n=3), who were included with the other types of cancer. This may be perceived as a under representation of lung cancer patients considering it is the most common type of cancer at population level in the United Kingdom. This was not the case. The entire population from the region under examination were included in the sample, however from 54 patients diagnosed with lung cancer during the one year time frame examined, only 12 of these patients were still alive at the time of the distribution of the questionnaire. Therefore it could be said that lung cancer patients were under-represented in this study, but the reason for this is the high mortality rate of this patient group.

Fifty nine percent of patients received their diagnosis as outpatients and 78% of respondents underwent surgery with 41% and 39% undergoing chemotherapy and radiotherapy respectively.

### Information and support received

Likert scales were utilised to record patients' views of the information and support they had received during their diagnosis and treatments. Seventy-three percent of respondents indicated that they had received the right amount of information, none-the-less 31% would have liked more information. Only 6% of respondents felt that there was too much information given at one time. Most patients (72%) agreed with the statement that information and explanations helped them with their anxiety. Support from family and friends was rated highly (by 93%). Regarding the amount of support after treatment is completed, mixed results were elicited: 31% felt there was not enough support, 44% disagreed and 17% were unsure. In-depth analysis was undertaken whereby the population was divided into the sub-groups as outlined in Table 2. Chi-square testing was used to determine if differences existed between the groups. No significant differences were found with the first six statements, however the last statement entitled: 'I feel that someone who has had cancer can provide support for others', demonstrated a significant difference ( $p<0.001$ ). The possible explanation was that the group of patients with bladder, prostate or kidney cancer were the group who mainly disagreed with the statement.

### Sources of Information

Consultants were viewed favourably as sources of information by 84% of respondents and were the most popular source, with GPs second (62%). However 11% and 24% respectively rated them

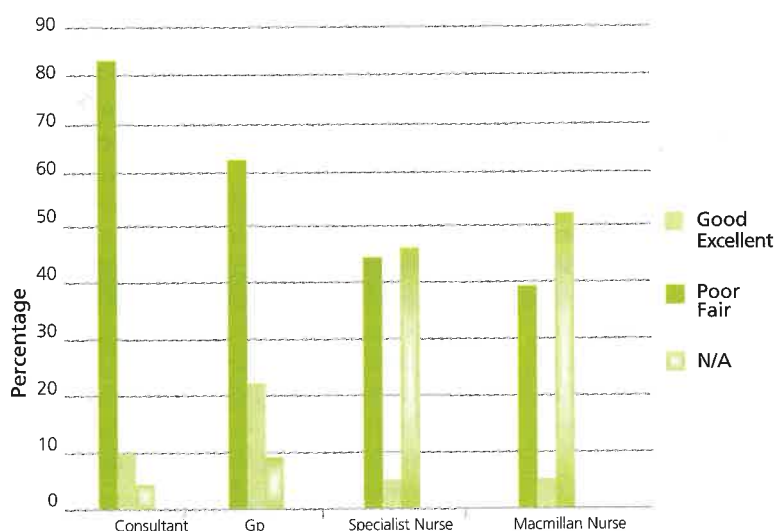


Figure 2: Percentage ratings of respondents for some medical and nursing professionals as sources of information

unfavourably, with 5% and 12% respectively feeling they were not applicable as a source of information. Chemotherapy (35%) and radiotherapy (36%) staff were viewed similarly as excellent or good by respondents, as were specialist (48%) and Macmillan (39%) nurses (see figure 2). Macmillan nurses are defined as specialist cancer nurses within the context of this paper. Specialist nurses are defined as site specific nurses in this paper (e.g. breast care, colorectal, stoma care etc.). However not all patients undergo further treatments or have the opportunity to avail of specialist or Macmillan nurses. Chi squared tests were carried out on the data and some groups demonstrated significance ( $p \leq 0.001$ ), namely chemotherapy and radiotherapy staff, specialist and Macmillan nurses, district nursing staff and books. Closer examination revealed possible explanations from respondents' ratings for professionals as excellent or good:

1. Leukaemia and lymphoma patients rated chemotherapy staff higher (63%) than any other group.
2. Radiotherapy staff were rated highly by 60% of patients in the breast cancer group.
3. Specialist nurses were rated highly (79%) by the breast cancer group.
4. Patients who had either leukaemia / lymphoma and those who had breast cancer rated Macmillan nurses favourably with percentages ranging between 47% and 58% for the respective groups. As a source of information, Macmillan nurses were rated as 'not applicable' by 77%, who had prostate/bladder/kidney cancer and 72% who had gynaecological cancers. These results might reflect the apparent absence of referral to Macmillan nurses for these groups.

Ward nursing staff were rated higher than district nursing staff with ratings of 65% compared to 36% for district nursing staff. Family and friends were the fourth most popular source of information (59%).

Written information was rated poorly with only 29% of respondents considering it favourably and 42% considering it to be not applicable as a source of information.

#### Problems encountered by patients

When asked about commonly reported problems, patients reported dealing with problems most frequently and coping with treatments next (see table 3). Further analysis was carried out using the groups and the following results revealed:

- Problems with respondents' social life and sex life were the third and fourth most commonly reported problem respectively
- Choosing between treatments was the least common reported problem.

#### Development of an information centre

The second part of the questionnaire elicited patients' views on the establishment of an information centre. A list of 21 different types of information and support services was rated on a scale of 1 (least useful) to 9 (most useful). The most popular and least popular items can be seen in table 4.

Respondents (97%) reported access to a telephone and 18% reported access to the Internet. Most respondents (87%) were willing to travel to an information centre and the majority wanted the centre hospital-based and open during office hours. When asked how often patients would use such a service, 88% ( $n=276$ ) reported they would visit 1-4 times. Sixty four percent of respondents felt an information centre would make a difference to them.

In relation to the preferred staffing of a centre, 73% viewed it to be specialist nurses, with doctors (40%) rated as second. Doctors were second choice as information providers at a centre as opposed to the first choice during diagnosis and treatment.

The final question asked patients for further comments and 46% of respondents answered. The most commonly reported problems were:

- delay in referral from GPs
- communication problems between professionals and
- patients' desire to have family present at time of diagnosis.

#### Discussion

As the population studied was designed to be representative of patients in the catchment and was not subject to any sampling procedure, the findings reflect the majority viewpoints. They also have relevance to similar groups of patients elsewhere. The remit of the study was broad as it attempted to address all patients' views of their information needs following a diagnosis of any cancer.

**Table 3: Problems most commonly reported by respondents, in descending order of occurrence**

Problems	n	%
Dealing with symptoms	82	27
Coping with treatments	77	25
Social life	60	20
Sex Life	52	17
Obtaining benefits	47	16
Returning to work	42	14
Talking to family/friends	26	9
Choosing between treatments	11	4



**Table 4: Most desirable and least desirable features of a proposed cancer information centre.**

1. Someone to explain things
2. Education about the disease /treatments
3. Access to specialist nurses
4. Advice on symptom control.
.....
97. The Internet
98. Exercise classes
99. Relaxation classes
100. Video library

#### General satisfaction with information and support

The results of this study indicate that generally two thirds of patients were satisfied with the information they received, and this finding was not specific to any one group. Respondents' were satisfied that the right amount of information had been provided and received. Indeed patients are generally satisfied with the information they receive (Veronesi et al, 1999; Codd, 1999; Luker et al, 1995; Luker et al, 1996). However Chalmers et al (2001) found two thirds of patients (n=39) felt their information needs were not met. The majority of respondents (59%) received their diagnosis as an outpatient, which has implications in the development of new services, which tend to be in-patient focused.

Even though over two thirds expressed that their information needs were met, many still wanted more information. However, as the design of the study was extensive rather than intensive, exactly what these information needs are was not fully uncovered. This finding corresponds with Lazarus and Folkman's (1984) postulation that when a situation is threatening, a person will seek information to better understand what is happening. Patients' need and desire for information has been described as enormous (Suominen et al, 1995).

The extent to which other patients were called upon for support varied significantly ( $p<0.001$ ) amongst the groups, and can be explained by the lower percentage of respondents with bladder/prostate/kidney cancer. On analysis it was found that the majority of these patients were male (85%). Leydon et al (2000) found women utilised other patients for support and information about treatments more so than men. Men tended to rely more on their partners and family, which could explain why this group differed from the other groups.

Nearly half of the respondents expressed doubt concerning the amount of support available on completion of treatment. Support for this finding can be found in one study of nurses whereby, one third of nurses considered that after hospitalisation the

patient should be given information, and only on request (Suominen et al, 1995).

#### Sources of information

As providers of information, consultants and GPs were identified as the most popular sources of information. Interestingly, when asked about their desirability at an information centre they were rated second to specialist nurses as the most preferred professionals. On this issue, no significant differences were noted amongst the different groups. Within the literature, support exists confirming the suggestion that consultants were the most preferred and used source of information (Meredith et al, 1996; Bilodeau and Degner, 1996; Hinds et al, 1995; Slevin et al, 1996; Luker et al, 1996; Veronesi et al, 1999).

Ward nursing staff scored highly by most respondents (65%). Slevin et al's (1996) study supports this finding, reporting that 50% of respondents rated ward sisters as a valuable source of information. Wilkinson (1991) and Ödöling et al (2002) suggest that once patients have been given a cancer diagnosis, nurses become more reticent in giving them information and distance themselves from patients. Harrison-Woermke and Graydon, (1993) found nurses' understanding of patients' information needs were diversely misplaced in comparison to patients' expressed information needs. Findings from this study appear to contradict this.

Links between hospital care and primary care appear, from the results, to be problematic. Perhaps lack of communication may be a reason for the large amount of respondents who viewed district and Macmillan nurses as not applicable as a source of information. Other sources such as patient support groups and voluntary organisations were viewed as not applicable in providing information. Reasons for these findings are not known. A possible reason can be found in other studies which report that patients perceive they received little useful information from voluntary services and support groups (Luker et al, 1996; Slevin et al, 1996; Boudioni et al, 1999; Veronesi, 1999; Codd, 1999). Respondents' views of information sources from TV/radio programmes and books rated low when examining the literature. Shingler's (1997) study contradicts this finding suggesting that 100% of respondents utilised these sources.

#### Methods of information-giving

Written information rated poorly in this study (29% rated it favourably), and did not demonstrate any statistical significance between the different groups. Substantial support for this finding is available in the literature, with many studies reported that only 20% - 50% actually receive written information (Cheater

et al, 1999; Scriven & Tucker, 1997; Loge et al, 1997). Some possible reasons for the poor view of written information can be derived from the literature. Scriven and Tucker (1997) and Harris (1997) whilst examining the content and presentation of written information presented to patients found many problems with accuracy, content, quality and dissemination.

#### Problems encountered by patients

Problems rated of least importance were patients' emotional problems, adjustment to life at home and work, spiritual needs and family relationships which are supported by Wiggers et al (1990). Choosing between treatments was the least reported problem which may be due to deference to the opinion of the appropriate consultant, rather than the assumption that patients were fully informed of treatment options and satisfied with the treatment selection.

Difficulties encountered in respondent's sexual and social lives were reported less frequently as problems, a finding that is supported by the literature (Corney et al, 1992; Davison et al, 1995; Luker et al, 1996). However in the list provided these areas were rated fourth and fifth respectively, suggesting the need to address them since patients' do report them as problems, even if less frequently than problems related to treatments and symptoms.

#### Development of an information centre

A need for the development of a cancer information centre has been identified. Some information centres have already been developed in the United Kingdom, some within hospital grounds and others outside hospital premises. They are staffed by health care professionals and provide information in varied forms, such as verbal information from professionals, books, journals, computer and the Internet.

Better written information, access to specialist nurses and a better knowledge of voluntary agencies, support groups and the function of social workers would be key areas, which could be targeted, if a centre were developed. Eighty one percent of respondents supported the idea of an information centre and felt it would have made a difference to them.

Griffiths and Leek (1995) identified an information centre as the most frequently identified gap between needs and resources for patients following a diagnosis of cancer. However, current

fiscal realities may mean that the development of cancer information centres may be limited. Nonetheless these findings support the improved use of services to better inform patients, and can be utilised to guide and inform staff of patients' expressed needs within currently available resources.

#### Conclusion

Utilising only one research approach allows for a limited examination of the facets of the topic to be examined. Consequently, this poses limits upon the validity of the research. Questionnaires themselves provide further limitations, as generally only those who are literate and well motivated will complete them. These limitations apart, the findings of this study suggest that patients are generally satisfied with the information they receive, however they still have significant unmet information needs. Sources of information are important to patients yet some valuable sources of information are currently under-utilised.

The results demonstrated areas, which deserve special attention, namely written information, improving communication between primary, secondary and tertiary care providers and the need for the development of cancer information centres. Written information should be utilised with high quality verbal communication. Links with primary care should be strengthened to ensure information services are available to the patients.

In summary, these findings serve to sensitise and influence health care professionals' perceptions and guide them in the importance of providing good information for patients. This quantitative research study and associated recommendations has examined a crucial area in the care of people with cancer. This approach was deliberately selected in order to facilitate a wide expression of opinion. Whilst significant in terms of the number of respondents, this research forms only a part of what surely needs to be a holistic description of the information needs of people with cancer.

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